

Home- and community-based care services: identifying consumers and needs in a rural Western Cape Province setting

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DECLARATION

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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ABSTRACT

Background: Person-centredness is an aim of the Home- and Community-Based Care service, where users' needs always take priority. Identifying users and their needs is vital to quality services.

Objectives: The dual aims of the study were to determine who the Home and Community Based Carers in the study setting view as the consumers of their services, and to identify the needs of these consumers.

Method: An explorative, qualitative study was done. Home and Community-Based Carers ($n=5$), patients ($n=9$) and family caregivers ($n=5$) providing or using the Home- and Community-Based Care service in Caledon (Western Cape, South Africa) participated in the study. Convenient sampling was done. Data was collected through a focus group discussion with the carers and semi-structured interviews with the users and family caregivers. Thematic analysis of data was done. All relevant information related to the study was explained to the participants and informed consent was obtained. The anonymity and confidentiality of all participants was protected throughout the study.

Findings: The Home- and Community-Based Carers viewed the community as the users of their service. The community refers to the residents of Caledon as any resident could benefit from the service. Family involvement, privacy and relationship-building are crucial to Home- and Community-Based Care service in Caledon. Themes from user interviews included: user experience of the service; impact of the service; services received; communication breakdown and suggestions for improvement. Users were mostly satisfied with the service and found it acceptable. Their needs were being met, but they expressed a need for further training and guidance related to the management of specific health conditions. Findings indicated challenges with referral to other levels of health care. Users had recommendations on how the service could improve, for example longer working hours, employing male caregivers, consistency of service delivery and increasing the stipend that the carers are currently earning.

Conclusion: The Home- and Community-Based Carers provided a valuable service to the entire community of Caledon. The needs of the users were mostly met and most users had a positive experience of the service. The study identified gaps related to further education, interaction with family carers and referral to other services.

Recommendations: Recommendations include: the development of a contact platform with clinic staff; education of Home- and Community-Based Carers on referral pathways and

sources of support; developing or use of scope of practice guidelines; training on specific health conditions and practical suggestions that might improve working conditions.

Key words: home- and community-based care; patient-/person-centred care; user needs

ABSTRAK

Agtergrond: Persoon-gesentreerdheid is 'n doelwit van die Tuis en Gemeenskap Gebaseerde Versorgings dienste waar die verbruiker se behoeftes altyd geprioritiseer word. Identifisering van verbruikers en hulle behoeftes is noodsaaklik vir kwaliteit dienste.

Doelwitte: Die doelwitte van die studie was om te bepaal wie die Tuis en Gemeenskap Gebaseerde Versorgers sien as die verbruikers van hulle dienste, en om die behoeftes van die verbruikers te bepaal.

Metodologie: Die studie was ondersoekend en kwalitatief van aard. Tuis en Gemeenskapversorgers ($n=5$), pasiënte ($n=9$) en familie versorgers ($n=5$) wat versorging bied of gebruik maak van die Tuis en Gemeenskaps Gebaseerde Versorgings dienste in Caledon in die Wes-Kaap, het deelgeneem aan die studie. Toevallige steekproefneming is gedoen. Data was ingesamel deur 'n fokus groep bespreking met die Tuis en Gemeenskaps Gebaseerde Versorgers en semi-gestruktureerde onderhoude met verbruikers en familie versorgers. Tematiese analise van data is gedoen. Alle relevante infromasie rakende die studie was verduidelik aan die deelnemers en hulle het die reg gehad om die weier om deel te neem aan die studie. Deelnemers is meegedeel dat hulle anoniem sal bly en dat alle data vertroulik gehanteer sal word.

Bevindinge: Die bevindinge het aangedui dat die Tuis en Gemeenskaps Gebaseerde Versorgers die gemeenskap as die verbruikers van hulle diens sien. Die gemeenskap verwys na die inwoners van Caledon aangesien enige inwoner kan baatvind by die dienste. Familie betrokkenheid, privaatheid en die bou van verhoudings is belangrik vir die Tuis en Gemeenskaps Gebaseerde Versorgings dienste in Caledon. Temas vanuit verbruiker onderhoude sluit in: verbruikers se ondervindinge van die diens, impak van die diens, dienste ontvang, kommunikasie afbreuk en aanbevelings vir verbetering. Die meeste verbruikers was tevrede met die diens en het dit aanvaarbaar gevind. Hulle behoeftes is bevredig, maar hulle het 'n behoefte vir verdere opleiding en leiding rakende die hantering van spesifieke mediese kondisies. Die bevindinge dui op uitdagings met die verwysing na ander vlakke van gesondheids sorg. Verbruikers het aanbevelings gemaak rakende diensverbeterings byvoorbeeld langer werks ure, aanstel van manlike versorgers, konstantheid van diens lewering en die verhoging van die lone wat die Tuis en Gemeenskaps Gebaseerde versorgers hulle verdien.

Opsomming: Die Tuis en Gemeenskaps Gebaseerde Versorgings dienste lewer 'n waardevolle diens aan die hele gemeenskap in Caledon. Die behoeftes van die verbruikers

is bevredig en die meerderheid van die verbruikers het die diens as positief ervaar. Die studie het ook leemtes geïdentifiseer rakende verdere opleiding, interaksie met familie versorgers en verwysing na ander dienste.

Aanbevelings: Aanbevelings sluit in die ontwikkeling van 'n kontak platform met die kliniekpersoneel; opleiding van Tuis en Gemeenskaps Gebaseerde Versorgers rakende verwysings-prosedure en bronne van ondersteuning; ontwikkeling en of gebruik van omvang van praktyk riglyne; opleiding oor spesifieke gesondheids toestande en praktiese aanbevelings wat werksomstandighede mag verbeter.

Sleutelwoorde: Persoon-gesentreerde dienste; Tuis en Gemeenskaps Gebaseerde Versorging, Verbruiker se behoeftes

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LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
CBO	Community-Based Organisations
DOH	Department of Health
FBO	Faith-Based Organisations
HBC	Home-Based Care
HCBC	Home- and Community-Based Care
HCBCs	Home- and Community-Based Carers
HIV	Human Immunodeficiency Virus
NGO	Non-Governmental Organisation
PHC	Primary Health Care
WHO	World Health Organization

GLOSSARY

Community-Based Care: Care that “the consumer can access nearest to home, which encourages participation by people, responds to the needs of people, encourages traditional community life” (National Department of Health, 2001:1)

Consumer: “A person who buys good or uses services” (Oxford Advanced Learners Dictionary, 2010:312)

Home Care: “The provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person’s maximum level of comfort, function and health including care towards a dignified death” (National Department of Health, 2001:1)

Person-centredness: “A philosophy of care that encourages: (a) shared control of the consultation, decisions about interventions or management of the health problems with the patient, and/or (b) a focus in the consultation on the patient as a whole person who has individual preferences situated within social contexts (in contrast to a focus in the consultation on a body part or disease)” (Dwamena, Holmes-Rovner, Gaulden, Jorgenson, Sadigh, Sikorskii, Lewin, Smith, Coffey, Olomu & Beasley, 2012).

CHAPTER ONE

FOUNDATION OF THE STUDY

1.1 INTRODUCTION

Home- and community-based care (HCBC) is an essential component of Primary Health Care (PHC) and part of the health care continuum (DOH, 2001). It is usually provided in the home of the consumer by community health workers with the aim to enable consumers to remain in their home environments. Non-profit organisations provide HCBC to communities in the Western Cape (Western Cape Government Provincial Treasury, 2011:19). An audit within the Western Cape in 2004 determined that the HCBC service served 8 783 households, with 54 476 household members (Klaas-Makolomakwe, G. & Prince, C. 2005:15).

HCBC initially started in response to the increased prevalence of Human Immunodeficiency Virus and Acquired Immunodeficiency Syndrome (HIV–AIDS), but has since evolved, and now provides services to any person who needs assistance due to a health condition, impairment and/or resulting disability. For this reason, the roles of home- and community-based carers (HCBCs) can be quite diverse and user expectations and needs differ, based on their individual circumstances and health care requirements (Aantjes, Quinlan & Bunders 2014; Moetlo, Pengpid & Peltzer 2011; Tsolekile, Puoane, Schneider, Levitt & Steyn, 2014). To provide a person-centred service, HCBCs must have a clear understanding of who the users of their services are, and what the needs of these users are in the community that they serve.

Thus far, research on HCBC in South Africa has focused mainly on persons living with HIV or AIDS. Example of this is the evaluation of the integrated CBHC model conducted by Uys (2001) and the identification of community-based programmes for persons living with HIV or AIDS (Russell & Schneider 2000). Research has also been undertaken to audit Home- and Community-Based Organisations in South Africa (Ogunmefun et al, 2011) as well as in the Western Cape (Klaas-Makolomakwe & Prince, 2005). There is a lack of research on HCBC services for patients with other health needs including disabilities.

1.2 STUDY PROBLEM

According to the national guidelines on HCBC, it is the responsibility of the organisations that provide HCBC to identify their consumers (National Department of Health, 2001). However, the organisations do not deal with the consumer directly. HCBCs employed by the

organisation deal with consumers daily. Thus it is necessary to identify who the HCBCs see as their consumers.

HCBC aims to promote person-centredness; thus consumers' needs should always take priority. Once HCBCs know who their consumers are, they can start to identify their consumers' needs. The needs of the consumers of HCBC services in the Caledon Community have never been formally identified.

1.3 STUDY AIMS

The dual aims of the study was: to explore who the HCBCs in the study setting viewed as the consumers of their services, and to describe the needs of these consumers.

1.4 STUDY OBJECTIVES

- To explore who the consumers of HCBC are in the study community
- To explore the experiences of consumers of HCBC in the study community
- To explore the type of services provided by HCBCs in the study community

1.5 STUDY SIGNIFICANCE

The study will hopefully contribute to filling the gap of limited literature related to HCBC in South Africa, in addition to identifying questions for future research. The identification and definition of the consumers, and description of their self-identified needs, may be a first step towards improving services and making them more person-centred. HCBCs might develop a better understanding of the needs and challenges experienced by consumers accessing their service. Consumers will have the opportunity to voice their needs enabling them to participate in their own caregiving process enhancing their sense of worth and value. The study also sets a platform for the HCBC to build vital relationships with the consumers and family members in Caledon and understanding their needs, with implications for roll-out to the Overberg District, the Western Cape and South Africa.

1.6 MOTIVATION FOR THE STUDY

I developed an interest in PHC and HCBC after completing an assignment regarding the accessibility of a PHC facility for people with disabilities. Based on the findings of that assignment, I started to consider possible research questions regarding the HCBC service in Caledon. As the HCBC service in Caledon continues to grow in response to the needs of the community, more HCBCs will be employed. These HCBCs must know who their consumers are to enable them to determine their consumers' needs.

I selected Caledon as my community of interest due to the findings from that original assignment, but also because I am a proud member of the Caledon community. I hope to use the findings from this study to enhance the quality of health care that the HCBCs are providing to the consumers of the HCBC service in Caledon.

1.7 SUMMARY

Areas like HIV and AIDS are well researched in relation to HCBC. However, HCBC service provision to other users, including persons with disabilities, is less well researched. Thus this study evolved in the area of service provision. It aimed to explore the HCBCs' view of who their consumers are, and aimed to identify the needs of these consumers. It is hoped that the information will assist to improve the services and strengthen the person-centred focus of the service.

1.8 CHAPTER OUTLINE

Chapter One: Foundation of the study

Chapter One provides background information on HCBC services and focuses the study through presenting the problem, aim and objectives.

Chapter Two: Literature review

Chapter Two explores past and current knowledge and trends in HCBC through a review of the literature.

Chapter Three: Research methodology

Chapter Three explains the choice of a qualitative methodology and methods used in the study.

Chapter Four: Findings

The findings are presented in Chapter Four.

Chapter Five: Discussion

The findings are discussed in Chapter Five.

Chapter Six: Limitations, recommendations and conclusion

The final chapter looks at the study limitations, provides recommendations and draws conclusions from the findings.

CHAPTER TWO LITERATURE REVIEW

2.1 INTRODUCTION

This chapter presents an overview of literature related to the study question. The literature review looks at the history of the development of HCBC in South Africa. The chapter continues to cover the scope and availability of the service concluding with needs of the consumers using the services.

2.2 HOME- AND COMMUNITY-BASED CARE: ROLE AND HISTORY

HCBC is a component of comprehensive PHC (Russell & Schneider, 2000). PHC in South Africa originated with the concept of Community-Oriented Primary Care, as developed and pioneered by Sidney and Emily Klark at the Pholela Health Centre in the old Natal Province, in 1940. Community-Oriented Primary Care is the continuous provision of care to a clearly specified community, based on the assessment of their health needs (Mullan & Epstein, 2002). Health promotion and education as well as preventive, curative, rehabilitative and palliative services are integrated into a comprehensive community-based package. Community members are trained as health assistants and educators to extend the capacity of professional service providers and to assist with skills development, and health education and promotion in households (Kautzky & Tollman, 2008). Community-Oriented Primary Care is underpinned by the provision of accessible, continuous and accountable health care services where the focus is on prevention, promotion and community participation within a multidisciplinary team based on the health needs of community (Longlet, Kruse & Wesley, 2001).

In 1948, the National Party gained power in South Africa. This change of government led to the rise and legislation of the apartheid¹ system. Community-Oriented Primary Care struggled to continue to exist and had collapsed by 1960 (Kautzky & Tollman, 2008). Public health care became institutionalised; private health care services, utilised almost exclusively by advantaged minority race groups, flourished. According to Kautzky & Tollman (2008), racial segregation, as well as ineffective and insufficient management of the public health care sector, negatively influenced health care during the period of 1970–1994. In response, non-governmental organisations (NGOs) and community-based organisations (CBOs)

¹ Apartheid – a word from the Afrikaans language (with original roots in Dutch), literally meaning ‘separateness’ (Oxford Dictionaries, 2013). *Apartheid* refers to the system of segregation or discrimination on grounds of race, legally enforced in South Africa from 1948, with preliminary relaxation in 1990, until first democratic elections in 1994.

developed increasingly to try to address the needs of citizens through community and home-based intervention (Kautzky & Tollman, 2008; Aantjes *et al.*, 2014.)

With South Africa's first democracy in 1994 came a new dispensation which fostered equality. This laid the foundation for the development of new policies, including the National Health Plan, which was developed by the African National Congress (ANC) prior to 1994 and was based on the earlier locally conceptualised Community-Oriented Primary Care and the international Alma-Ata Declaration of 1978 (Kautzky & Tollman 2008). According to the National Health Act of 2003 (Republic of South Africa, 2004) and various subordinate acts, policies and position papers such as the *White Paper on the Transformation of the Health System in South Africa* (South African Department of Health, 1997) the *Green Paper on National Health Insurance* (South African Department of Health, 2011a), the *Negotiated Service Delivery Agreement* (South African Department of Health, 2011b) and *The National Development Plan 2030* (South African Government, 2011), health care in South Africa should be provided within the PHC philosophy (Coovadia, Jewkes, Barron, Sanders & McIntyre, 2009; Kautzky & Tollman, 2008; Naledi, Barron & Schneider, 2011). The *implementation* of PHC in South Africa should be via the mechanism of the District Health System (Phaswana-Mafuya, Petros, Peltzer, Ramlagan, Nkomo, Mohlala, Mbelle & Seager, 2008).

However, in many areas, PHC remains inaccessible to individual South African citizens. Multiple barriers such as the focus on curative services; top-down decision-making by provincial Departments of Health; inadequate managerial structures at district and sub-district level; fragmented, inequitable services; vertical, uncoordinated, disease specific programmes; challenges with referral systems, as well as poor co-ordination at facility level, hinder the implementation of the District Health System and Primary Health Care (Naledi *et al.*, 2011; South African Government, 2011).

The District Health System must collaborate with organisations that often provide HCBC services such as NGOs, CBOs and Faith-Based Organisations (FBOs) (Phaswana-Mafuya *et al.*, 2008). The services that are provided by these organisations are valuable and crucial to various communities (Department of Social Development, 2006). In the current mode of Primary Health Care service delivery in South Africa, the District Health System, sub-districts and civil society organisations should be linked in a continuum of care where they influence and support one another in a significant manner. HCBC is part of this continuum of care and not a service that exists separately from other services (Russell & Schneider, 2000).

2.3 HOME- AND COMMUNITY-BASED CARE IN SOUTH AFRICA

HCBC has been implemented on an informal basis for many centuries (Jackson, 2007) and it is developing continuously in countries all over the world (World Health Organization, 2000). Home-Based Care is viewed as care that is provided in the home by caregivers through both the formal and informal health sector (National Department of Health, 2001). Community Based Care is care that “the consumer can access nearest to their home, which encourages participation, responds to the needs of people, encourages traditional community life and creates responsibility” (National Department of Health, 2011:1). HCBC can therefore be seen as care (formal or informal), which consumers (beneficiaries) are able to access within their home or close to their home environment.

The overarching goal of HCBC is to ensure that consumers stay independent with the best quality of life through the provision of hope and appropriate care. The service primarily draws on the strength of families and communities, who form the basis of the service (De Wet, 2012; World Health Organization, 2002).

In its formal form HCBC is provided by Community Health Workers (CHW) with some training, who work either as volunteers or for remuneration (De Wet 2012; Mataure & Thupayagale-Tshweneagae, 2013; Morton, Mayekiso & Cunningham, 2013). The Community Health Workers (CHW) are generally from the same communities as their clients and often live in close vicinity to clients. They might face the same socio economic and health challenges as their clients (De Wet 2012; Morton *et al.*, 2013). They serve as a community information service and create an accessible point of health care service delivery based on community needs (Jack, Jenkins & Enslin 2010; Moetlo *et al.*, 2011). Increased demands on the health system and costs related to health care have increased the need for HCBC services (Ncama, 2005). They have grown quite substantially in the last two decades in South Africa due to shorter periods of patient hospitalisation, in combination with the increase of chronic conditions such as HIV-infection and/or AIDS (Aantjes *et al.*, 2014; De Wet, 2012; Mataure & Thupayagale-Tshweneagae, 2013). While HCBC was initiated in response to the HIV epidemic, it has evolved and currently services are often extended to all needing home care and not only people with HIV and/or Aids (Aantjes *et al.*, 2014). HCBC covers a wide variety of services that incorporate physical, psychosocial, palliative and spiritual aspects (Ncama, 2005).

The South African Department of Health (Fox, Fawcett, Kelly & Ntlabati, 2002) recognizes five models of HCBC as set out in Table 2.1. These models differ in their organisation and coordination, as the driving force behind the models varies between Government sectors

and NGOs. However, all five models are located within communities and their holistic focus is the provision of services to patients and families (Moetlo *et al.*, 2011). The current study focusses on the integrated community home-based care model.

Table 2.1: Common models of Home and Community Based Care (Fox *et al.*, 2002)

Models of HCBC	Level	Coordinated by
1. Community-driven model	Community initiative, often isolated	Community developer
2. Formal government sector model	District level	Department of Health and Social Services
3. Integrated home/community-based care centre model	Care centres, often physical facilities that run support groups, income generating programmes, counselling and education services amongst others.	NGO
4. NGO home/community-based care model		NGO
5. Integrated community home-based care model	Collaboration between various partners and programmes, might be integrated into health services	NGO E.g. hospice association

The South African Hospice Association was one of the first NGOs to develop a model of care for HCBC, namely the Integrated Community Home Based Care model (Uys, 2001). At the current time, they implement programmes throughout South Africa. This integrated CHBC model provides comprehensive home-based care, whereby the client and family, community-based workers and hospices, clinics, hospitals and other CBOs, NGOs and FBOs form partnerships and are linked in a continuum of care (Ncama, 2005). The Integrated Home and Community Based Care model reflects a patient-centred approach with a specific focus on the patient and his/her family (Fox *et al.*, 2002). The Integrated Home and Community Based Care model is viewed as an ideal model for Home and Community Based Care (Mahilall, 2009; Fox *et al.*, 2002).

2.4 SCOPE, AVAILABILITY AND IMPORTANCE OF HCBC IN SOUTH AFRICA

According to the South African national guidelines on HCBC, the service should be directed at individuals with: communicable diseases (e.g. HIV and AIDS), non-communicable diseases (e.g. Hypertension, diabetes), persons with disabilities, older persons, persons requiring long-term care and those recovering from an illness (National Department of Health, 2001). South Africa has the largest number of people living with HIV globally, with an

estimated 5.6 million people infected (Nyirenda, Newell, Mugisha, Mutevedzi, Seeley, Scholten & Kowal, 2013). South Africa has the biggest Anti- Retroviral Program in the world with over 1.8 million people using anti-retrovirals (Mayosi, Lawn, Van Niekerk, Bradshaw, Abdool Karim & Coovadia, 2012). HCBCs play an essential role in the government's attempt to combat HIV and tuberculosis (TB) (Jack *et al.*, 2010). Due to the nature of HIV and AIDS, persons living with the virus are at high risk to develop secondary complications such as disablement and episodic illnesses (Hanass-Hancock & Nixon, 2009).

Non-communicable diseases (including neurological disorders, cardiovascular diseases, mental illness, cancer, diabetes etc.) accounted for 16% of disability-adjusted life years in 2000 in South Africa (Levitt, Steyn, Dave & Bradshaw, 2011). Cardiovascular diseases and diabetes place an individual at an increased risk of a cerebrovascular accident or stroke, which is the leading cause of adult disability in South Africa (Wasserman, de Villiers & Bryer, 2009). Community health workers (in the broadest sense of the term) have a crucial role to play in the lives of persons living with disabilities. Lorenzo, Van Pletzen and Booyens found that community health, rehabilitation and development workers in Botswana, Malawi and South Africa play a fundamental role in early identification and intervention of disabling conditions, advocacy and awareness raising with regards to disability, health education, development of support groups and intersectoral collaboration (2015).

HCBC also focuses on the elderly, and tries to meet the health care needs of older people to allow them to live in their homes rather than institutions (Bohman, Van Wyk & Ekman, 2010). With ageing, people might face more activity limitations as impairments related to vision, hearing, cognitive function and mobility set in. Their risk for disabling conditions such as stroke and dementia also increases (Harrison, Reeves, Harkness, Valderas, Kennedy, Rogers, Hann & Bower, 2012).

In general, HCBC services encompass a wide spectrum of services including basic nursing care, clinical care, dispensing medication, assistance with basic activities of daily living, health education and counselling (Aantjes *et al.*, 2014; Moetlo *et al.*, 2011; Tsolekile *et al.*, 2014). Furthermore, HCBC includes functional restoration, palliative care, pain relief, social support, livelihood support, legal support, nutritional support, transport, referral to clinical health care services, empowerment, child protection, health promotion and prevention (Aantjes *et al.*, 2014). HCBC also comprises development of persons with disabilities, and promoting participation in economic activities (Lorenzo *et al.*, 2015).

A PHC re-engineering strategy was introduced in 2011 in an attempt to improve health outcomes for South African citizens by reducing systemic barriers such as the inefficient

District Health System and the separation of community-, home-and health-care facility-based functions from one another (Naledi *et al.*, 2011). One of the actions of the PHC re-engineering strategy is to utilise community health workers as core members of a Primary Health Care Outreach Team to create a link between health facilities and consumers (Naledi *et al.*, 2011; South African Government, 2012). Within the teams their function will be screening, referral to health care facilities, health education, monitoring adherence, home visits, multi-disciplinary collaboration and support to consumers (Mayosi *et al.*, 2012). One of the proposed actions to strengthen health services and alleviate poverty in the National Development Plan 2030, is to enhance human resources in the health sector through the utilisation of 700 000 community health workers (South African Government, 2011).

Even though HCBCs can play a pivotal role in addressing the human resources crisis in health in South Africa (Tsolekile *et al.*, 2014) studies have found their services to be inadequate due to specific challenges. Home-based care (HBC) services often suffered from poor co-ordination (Wasserman *et al.*, 2009; Hassan, Visagie & Mji, 2011a; Cawood & Visagie, 2015; Jack *et al.*, 2010, Levitt *et al.*, 2011). A study done in the Vhembe District in Limpopo Province by Rudzani, Netshandama & Francis (2016) identified challenges such as unfulfilled promises, infrequent visits, and lack of trust and provision of poor quality assistive devices. Participants in two separate studies from the Western Cape Province of South Africa also mentioned a lack of professionalism as a challenge (gossiping and not keeping appointments) (Cawood & Visagie, 2015; Hassan *et al.*, 2011a).

A further challenge relates to a lack of knowledge which negatively impacted quality of care. Two sources found that community health workers had limited knowledge of health conditions and the information they provided to clients was not always accurate (Ncama, 2005; Tsolekile *et al.*, 2014). This might be due to a lack of training as identified by Jack *et al.*, (2010) and is aggravated by the significant range of health conditions they have to deal with (Jack *et al.*, 2010). Their training usually consists of either a basic five-day course or an advanced course of three to four weeks (Jack *et al.*, 2010). In addition to a general lack of knowledge, HBCs often lacked the training to manage people with conditions that require specific impairment-focused input, such as stroke. A study done by Wasserman *et al.* (2009) in northern Kwazulu Natal found that stroke survivors mostly received services from HBC providers. These HBCs however had no training with regards to stroke care and their services mainly focused on the provision of medical supplies, nursing care and health education. In another study done in the Vhembe District, South Africa, HCBCs indicated that they had inadequate knowledge regarding the management of hypertension and asthma as well as the provision of counselling (Moetlo *et al.*, 2011). According to Tsolekile *et al.*, (2014)

HCBCs lack knowledge with regard to provision of rehabilitation services in South Africa, even while they should play an important role in the rehabilitation program of individuals (Dawad, Jobson, Ganie & Quinlan, 2011)

HCBCs experience challenges that hamper service delivery. For instance, medications to manage pain and other basic pharmaceutical resources are not always available. Mashau, Netshandama and Mudau (2016) found that 80% of HCBCs from one region in Limpopo (n=190) experienced helplessness due to a lack of resources needed to assist the families under their care. The study by Mataure and Thupayagale-Tshweneagae (2013) indicated that a lack of medication, consumables and transport hampered their ability to provide services. A lack of funding is generally a problem since HCBC service delivery is mainly managed by NGOs (Ncama 2005).

Enabling patients to execute autonomy in their home was a major challenge for the HCBCs in a study done in Botswana (Shaibu, 2015). HCBCs also experience burnout (physical and psychological) along with rejection and stigma from the community that they reside in (Moetlo *et al.*, 2011). Physical (72%) and/or mental (8%) exhaustion was found to occur always or sometimes in the HCBCs who participated in the study by Mashau *et al.*, (2016). Jack *et al.*, (2010) described the varied responsibilities and high caseloads as well as challenges with regard to safety, patient compliance and disclosure of information on HIV status that HCBCs in George, South Africa faced. Moetlo *et al.* (2011) concurred that patient compliance created challenges to HCBC workers in delivery of services, and further found that lack of resources such as home-based care kits and transport money, challenges with supervisors and feeling unwelcome in the houses of some clients created further challenges, Morton *et al.* (2013) found that the effects of poverty such as substandard living conditions and food insecurity also challenged HCBC service delivery.

HCBCs however contribute to making a difference in the lives of their clients. Johnson and Khanna (2004) concluded that the home-based care program they studied in Kenya has a positive effect on the quality of life of persons living with HIV and/or AIDS. A systematic review on the roles and outcomes of HCBCs in HIV and/or AIDS care in Sub-Saharan Africa by Mwai, Mburu, Torpey, Frost, Ford and Seeley (2013) shows that HCBCs played a crucial role in HIV-related bereavement counselling of family members as well as ensuring that clients adhere to their antiretroviral treatment. Ncama (2007) conducted a study in South Africa with regards to disclosure of HIV status through the HCBC program, concluding that the service assisted in enabling individuals to accept their HIV positive status, and empowered them with the skills to disclose their status to family members and other significant people.

2.5 NEEDS OF CONSUMERS OF HOME- AND COMMUNITY-BASED CARE

Health care is usually organized around providers' priorities and views, not those of the clients or consumers (World Health Organization, 2008). However, HCBC forms an integral component of PHC, which is underpinned by the *batho pele* principles of placing people first (Klaas-Makolomakwe & Prince, 2005). *Batho pele* supports the need for consumers to be acknowledged and included in decision-making about their care which can be done by promoting person-centredness. According to Hunt (2013) person-centredness enables patients to be involved from the start of their care plan as goals are set and patients are viewed holistically. HCBC aims to promote person-centredness by taking culture, spirituality, belief systems, human rights and dignity of the person into account (National Department of Health, 2001; Moetlo *et al.*, 2011). According to the World Health Organization (2008:15), "person centeredness is not a luxury, it is a necessity" and by practising this, the HCBC service will be able to understand health consumers holistically within their natural or familiar environment. Meeting the needs of consumers impacts on their ability to live a valuable, meaningful life (Irwin & Ferris, 2008). Therefore, it is acknowledged that consumers' diverse health needs are specific to their individual circumstances and can change over time.

Consumers of HCBC face individual challenges that often do not fit textbook cases or are based on specific medical diagnoses, so HCBC services must be diversified to address a myriad of varying needs (Aantjes *et al.*, 2014; Crowe, O'Malley & Gordon, 2001; Rotondi, Sinkule, Balzer, Harris & Moldovan, 2007; World Health Organization, 2008). In a regional Zimbabwean study, Mataure & Thupayagale-Tshweneagae (2013) found that consumers had widespread and varying expectations of HCBC. Managing disease symptoms and access to medication featured alongside assistance with daily activities, providing information about their condition, their role in the family, counselling, respect for privacy, communication with care providers and financial assistance to buy food and pay school fees.

According to a review of the literature on the role of community health workers in HIV–AIDS care, they are expected to do the following: provide disease education; do needs assessments, disease screening and referral for diagnostic tests and treatment; offer support to adhere to treatment regimes; locate patients who defaulted on treatment regimes; offer nutritional screening and support; conduct life skills training; support patients and families; offer support to generate income through microenterprises; do training in gardening; assist with household chores, self-care and wound care (Mwai *et al.*, 2013). Aantjes *et al.* (2014) take a narrower view and state that HCBC should assist with obtaining antiretroviral treatment (ART) medication and provide for the nutritional, income and psychosocial needs of persons with HIV and/or AIDS in South Africa, Ethiopia, Malawi and Zambia (Aantjes *et*

al., 2014). Aantjes *et al* ascribe the decrease in physical needs to the roll-out of ART programmes (Aantjes *et al.*, 2014). Persons with HIV usually experience multiple losses: loss of self-worth and dignity, loss of autonomy and loss of support by loved ones; therefore psychosocial support is crucial (Moetlo *et al.*, 2011). Majumdar and Mazaleni (2010) state that 60% of patients with HIV and/or AIDS experience major depression. Aantjes *et al.* (2014) found that HCBC programs extended services beyond HIV-related issues to people with TB and malaria as well as basic nursing care for the elderly.

Education plays an important role in HCBC and a number of studies have found that patients and families want disease-specific, as well as general, education on prevention of diseases from HCBC providers (Mwai *et al.*, 2013; World Health Organization, 2001; Mataure and Thupayagale-Tshweneagae, 2013; Crowe *et al.*, 2001). A study done in Kenya found patients and their caregivers longed for education with regards to “basic nursing care, nutrition, universal precautions, administration of drugs, [and] use of medical supplies” (World Health Organization, 2001:34). Research done with individuals receiving mental health services within the community found that they had a need for information with regard to their illness, medication, treatment, treatment plan and human rights (Crowe *et al.*, 2001).

HBC all over the world relies on the strength of families and communities. Therefore, on a community level, the role of HCBCs includes awareness-raising campaigns, support groups and health promotion related to lifestyle and physical activity (Tsolekile *et al.*, 2014). Persons living with HIV experience stigma and discrimination in their communities and educating the community with regard to HIV–AIDS related matters is crucial (Majumdar & Mazaleni, 2010). Mataure and Thupayagale-Tshweneagae (2013) recommend that health education should be provided within a community context, and formal and informal counselling services must be available to consumers through the community. As community needs differ, it might be expected of HCBCs to deal with more than health-related issues, for example social problems (Tsolekile *et al.*, 2014).

The family forms the foundation of the HCBC team and it is the primary focus of care. Families should receive support from the community in which they live (World Health Organization, 2002). According to Kapp (2001) family members usually take the responsibility of caregiving upon themselves as it is seen as their duty; it is generally assumed that families will play the dominant role with regards to decision-making about care. Families caring for their loved ones commonly have difficulty with burden of care (WHO, 2000), but when families are acknowledged and integrated within care provision, they are better equipped to deal with their loved ones’ needs. Families might experience a sense of hopelessness and/or helplessness, and therefore feel dependent on HCBC services

(Motswasele & Peu, 2008). HCBCs should empower families and patient caregivers to take care of their *own* health (Motswasele & Peu 2008). Formal care should sustain informal care to minimise strain on informal caregivers (Majumdar & Mazaleni, 2010).

As presented in this exploratory literature review, HCBCs provide an essential service in their communities. Their job requirements are complex and varied in nature, dependent on consumer needs and possibly changing over time. This places a heavy responsibility on the shoulders of people who have their own households, face their own struggles with poverty and disease; have limited training and work for very little or no money. In the light of the strategic role that HCBCs play and the challenges they face, the purpose of this study was to explore HCBCs' understanding of their consumers and their consumers' needs.

2.6 SUMMARY

As the demand for health services in South Africa continues to grow, with the increase of communicable and non-communicable diseases, emphasis is placed on the health care system to meet the needs of health care consumers. Due to limited human resources, the use of Community Health Workers has become very prominent. HCBC services therefore play a pivotal role as they have become the bridge between health facilities and communities to ensure a continuum of care for health care consumers.

Until now, no study has been done to determine who the consumers/users of the HCBC service are and to identify their needs. This study addresses the need for consumer/user and needs identification.

CHAPTER THREE STUDY METHODOLOGY

3.1 INTRODUCTION

In this chapter, the use of a qualitative methodology is explained. The study setting and participants are introduced. The study processes, including community entry, data collection and data analysis are described. There were two participant groups: HCBC service providers and users of HCBC services. Identification of participants, data collection tools and data collection processes are described in separate sections for each group, which I have called Phase 1 and Phase 2. Finally, I looked at trustworthiness and confidentiality, as well as steps taken to ensure an ethical study.

3.2 STUDY DESIGN

An exploratory, qualitative study was done (Carter, Lubinsky & Domholdt, 2011) to explore a topic on which limited information is available. The chosen design is applicable to the study, as information on needs and opinions is best sourced through qualitative data.

3.3 STUDY SETTING

In the Western Cape Province of South Africa, there are 90 active non-profit HCBC organisations. Eight of these organisations are located in the Overberg District, of which the Caledon HCBC service forms a part (Western Cape Government Provincial Treasury Report, 2011). Caledon is in the Overberg District and falls under the Theewaterskloof Municipality. The town has a population of 13 971. Economic activities centre around business, agriculture, forestry and construction. The HCBC service in Caledon started in 2005 and the service uses the Integrated Home- and Community-Based Care model for their provision of care. The service employs 31 paid home- and community-based workers at any time. Their training includes information on HIV–AIDS, Tuberculosis (TB), Breastfeeding, Medical Male Circumcision, Child Health, Family Planning, Wound Care, Counselling, Antenatal and Postnatal Care. The HCBC service receives referrals mainly from the Caledon Provincial Hospital and Caledon Community Health Clinic. The Caledon Provincial Hospital is a secondary hospital with a seventy-five-bed capacity and a casualty department. The Caledon Community Health Clinic has been operational for thirteen years serving the population of Caledon and surrounding farm areas. Services offered at the clinic include: maternal-, mental-, school- and women's health as well as testing and treatment of communicable and non-communicable diseases, immunisations, healthy baby clinic, rehabilitation and treatment of minor ailments (Western Cape Department of Health, n.d.).

3.4 STUDY POPULATION, SAMPLING AND PARTICIPANTS

As mentioned previously, this two-phased study involved two different study populations: HCBC service providers and users of HCBC services.

3.4.1 Phase 1: HCBC service providers

The study population for Phase 1 consisted of the 31 HCBCs employed by the Home and Community Based Care services in Caledon during the period of data collection. HCBCs that were not available for participation during the data collection period due to various forms of leave, and those who declined participation, were excluded from the study population.

Out of the 31 HCBCs employed by the service, 11 indicated that they would like to participate in the study. It was decided to include all 11 in the study, thus a sample of convenience. On the date set for data collection, five HCBCs out of the 11 arrived at the pre-determined venue of their choice. These five participated in the study. Since findings from these five were similar and indicated a high level of data saturation, no effort was made to contact the remaining six HCBCs to collect additional data from them.

3.4.2 Phase 2: Users of HCBC services

The study population of users of the HCBC service included all primary users (patients) and family caregivers of users who received services from the HCBC service in the study setting from February–July 2016. The number of primary users was approximately 300 according to the HCBC database.

The manager of the HCBC service, in consultation with the staff, worked through their database of HCBC users and selected 22 potential primary user participants with a range of health conditions. The potential primary user participants were then grouped according to their health condition and gender, and participants were conveniently selected from each group (see Figure 3.1). Convenience sampling was used to identify nine primary user participants (patients). Family caregivers of these nine primary users were also invited to join in the study, but only five participated. According to Reid & Mash (2014) the sample size for qualitative data collection can be between 5-15 interviewees.

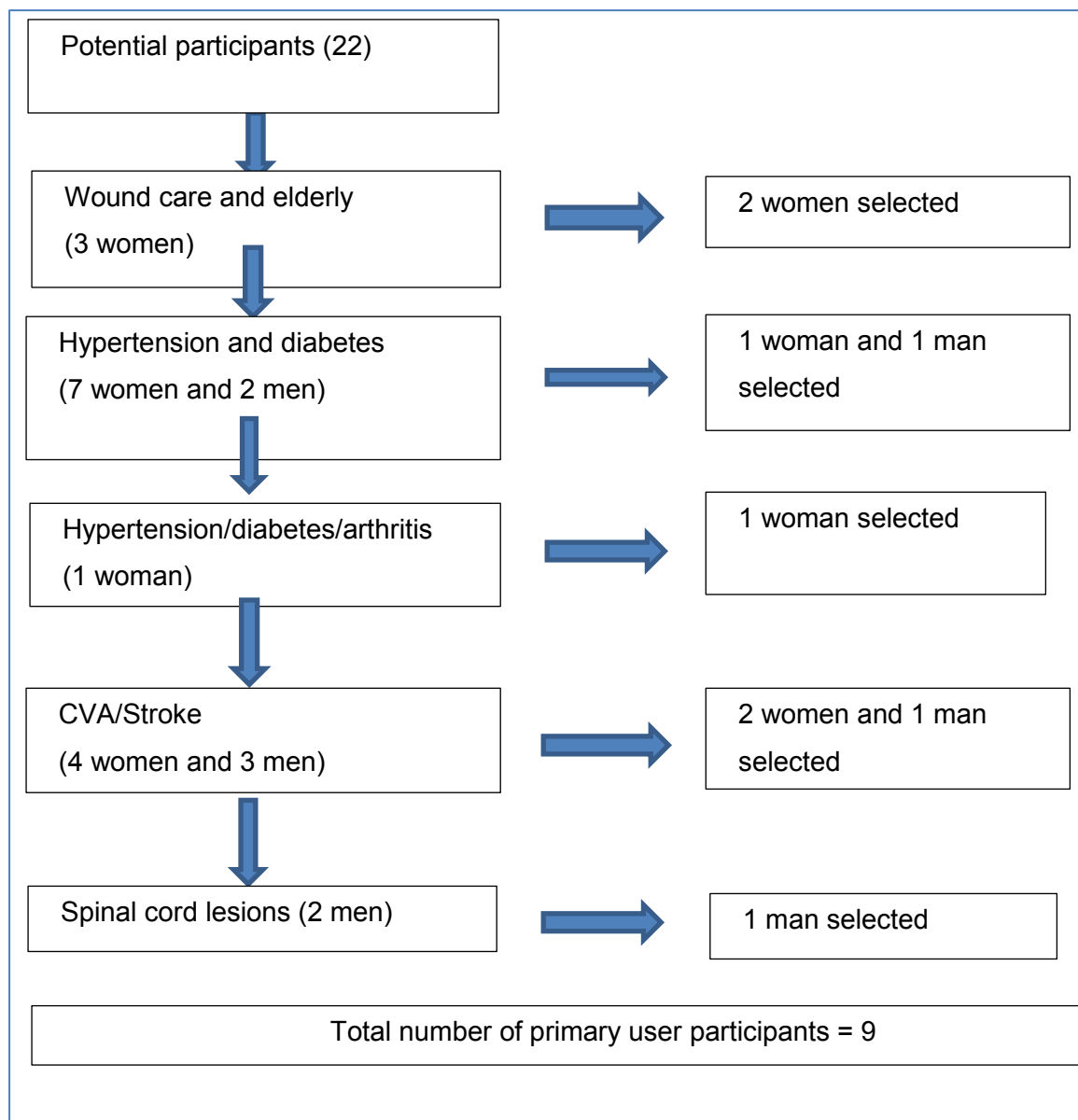


Figure 3.1: A schematic representation of the selection of primary user participants

3.5 DATA COLLECTION INSTRUMENTS

Three different data collection instruments were developed.

3.5.1 Phase 1: Data collection instrument for HCBCs

I developed a Focus Group Discussion Guide for data collection from the HCBCs (Appendix 6). The questions were based on the HCBC guidelines from the Department of Health, 2001. The questions were semi-structured enabling the participants to share their viewpoints and understanding. Through the use of the qualitative interview schedule the researcher could determine from the participants who they see as the consumer and why they are being seen as the consumer. The questions focused on the benefits of consumer identification, referral and assessment procedures (parties involved), along with the HCBCs' opinion of the role of families in caregiving (see Table 3.1).

Table 3.1: Data collection tools and methods

Participants	Data collection methods	Key questions
HCBCs (<i>n</i> =5)	Focus group discussion; duration 90 minutes	Who is the consumer? Referral process and initial assessment Role of family in care provision Importance of consumer identification
Primary user participants (<i>n</i> =9)	Semi-structured interviews; duration 15 minutes	Experiences of the service Areas in which the service helped Meaning of the service Service satisfaction Identification of needs Recommendations for service improvement
Family caregivers (<i>n</i> =5)	Semi-structured interviews; duration 15 minutes	Impact of the service Needs of family caregivers Benefits of consumer identification

Recommendations for improvement

3.5.2 Phase 2: Data collection instrument for users of HCBC services

I developed two interview schedules: one to guide the interviews with the HCBC service primary users and the second to guide the interviews with family caregivers (Appendix 7, Section A). The first section of both schedules covered socio-demographic and care provision information. The second section of the primary user participant schedule questions focused on: their experiences of the service; the impact that the service had on their life; what the service meant to them; their satisfaction with the service and what their primary needs were (summarised in Table 3.1). They were also given the opportunity to state what they felt HCBCs could do to improve their service. The family caregivers' interview schedule (Appendix 7, Section B) asked questions about: the impact of the HCBS on caregiving; family caregivers' needs; assistance that they require and benefits of knowing who the consumers are in caregiving. They were also given an opportunity to suggest how the HCBC service can be improved.

3.6 PILOT PROCESS

Phases 1 and 2 were piloted in Genadendal, a neighboring town of Caledon, with the HCBCs as well as users of their service. The purpose was to determine if there were any difficulties with methods and data collection instruments. After the focus group discussions with the HCBCs, I reflected on the questions used in the interview schedule, and the responses from the participants. I noted that I had to give a lot of guidance when I asked the HCBCs questions in the pilot focus group discussion. So I simplified the questions and added examples to ensure that the participants could understand the questions. I noted that at times the participants only provided a yes/no answer, which made me realise that I should use more prompting during the focus group discussion and interviews. I found that participants voiced their concerns about their health condition to the HCBCs, but they received no feedback from the HCBC coordinator. One participant noted that she valued the HCBCs' friendliness and the feedback they provide to their clients after they have received training. She noted that HCBCs assist the community during emergencies when community members must wait for the ambulance service from the nearest town. My experience and the results during this pilot process gave me the assurance that my questions on the interview schedule would elicit responses that would fulfil the study objectives.

3.7 DATA COLLECTION

3.7.1 COMMUNITY ENTRY

I made an appointment with the manager of the HCBC service in Caledon. The aim and objectives of the study were explained to her. I asked for permission to access the records of the HCBC services and for her support of the study. Permission was granted and support promised. On a date decided by the manager and me I went to the HCBC office and verbally explained the aims and objectives of the study, in Afrikaans and English, to the HCBCs. I explained that participation in the study was voluntary and they had the right to decline participation or to withdraw at any time. HCBCs who indicated that they would like to participate wrote their names and contact numbers on a participant list.

3.7.2 Phase 1: HCBC service providers

The 11 interested HCBCs were notified telephonically about the date, time and venue of the focus group discussion for data collection. The discussion was held in February 2016 at a local primary school in the Caledon community. On the day of data collection, only five of the 11 HCBCs attended the discussion. The focus group discussion was conducted in Afrikaans, with the mutual consent of all group members and it lasted 90 minutes. Each question was posed to the group and participants had to write down their ideas on a piece of paper. The participants then shared their answers with the group, and the ideas were written down on a flip chart. Each answer was discussed and everyone had the opportunity to give additional input. During the discussion of the answers, I probed for further clarification and gathering of information. The focus group discussion was recorded digitally.

3.7.3 Phase 2: Users of HCBC services and family caregivers

I visited each of the nine sampled primary user participants at home. I explained the aims and objectives of the study to them. I also informed them that their participation in the study was voluntary and that they had the right to decline participation or withdraw from the study at any stage. All of the sampled primary user participants consented to participate in the study. A time and date for the interview to be conducted was arranged with the participants. Interviews took place between 1 April and 31 July 2016.

I conducted and recorded all the interviews in the participants' homes. I interviewed the primary user participants (the HCBC user) first, and once that was completed then I interviewed the family caregiver. If the primary user participant was not able to communicate with me, then I only interviewed the family caregiver. I started off gathering the socio-

demographic information (see Table 3.2), before moving on to the second section of each interview schedule. The interview lasted an average of 15 minutes per participant. All interviews were done in Afrikaans.

Table 3.2: Demographic information of the HCBC user and family caregiver participants

User	Gender	Age group	Diagnosis/ needs from HCBC	Length of using service	Hours spent on caring by family caregiver daily
User 1	F	60–69	Wound care	< 1 year	
Family caregiver 1	F	< 18			6-9 hours
User 2	M	60–69	CVA	4–5 years	
Family caregiver 2	M	30–40			3–6 hours
User 3	F	60–70	Hypertension, diabetes & arthritis	2–3 years	
User 4	F	60–70	CVA	< 1 year	
User 5	F	70–80	Wound care & hypertension	2–3 years	
User 6	F	40–49	CVA	< 1 year	
User 7	M	50–60	Spinal Cord Injury	>5 years	
Family caregiver 7	F	50–60			>9 hours
User 8	M	60–70	Hypertension & diabetes	>5 years	
User 9	F	70–80	Hypertension	>5 years	
Family caregiver 10	F	60–70			>9 hours
Family caregiver 11	F	30–40			3–6 hours

3.8 DATA ANALYSIS

Data from Phases 1 and 2 was analysed simultaneously. Data was transcribed *verbatim*, by a former school secretary and analysed thematically in Afrikaans. Themes and narrative examples were translated by me for the purpose of this report. According to Braun & Clarke (2006), thematic analysis is performed when data is identified, analysed and reported in themes. I familiarised myself with the data through the process of immersion (Pope, Ziebland & Mays, 2000). It was at this stage that I started coding. Codes were divided into different themes and subthemes through the inductive approach. Themes were established, defined and named through a process of reviewing and refining (Braun & Clarke 2006). Data was analysed separately by the study supervisor who followed a similar process to the one described above. Once themes were established by both of us, we met, discussed each identified theme and how it was defined by us, with the ultimate outcome of reaching consensus on the themes.

3.9 TRUSTWORTHINESS

Credibility was addressed through triangulation of information from different sources (providers, primary users and family caregivers) and methods of data collection (focus groups and interviews) as well as through reaching consensus on the themes (Mabuza, Govender, Ogunbanjo & Mash, 2014). The transcripts were checked for correctness. Rival opinions from findings were included and explored. The methods and setting have been described. An audit trail and record-keeping system is available should anyone want to determine if findings can be transferred to other settings (Mabuza *et al.*, 2014).

3.10 ETHICAL CONSIDERATIONS

The study was approved by the Health Research Ethics Committee 1 of Stellenbosch University, Ethics reference number: S12/11/309 (Appendix 1). Permission was obtained from the Western Cape Department of Health and the Home and Community Based Care Head Office in the Overberg District (Appendix 2).

Participants were free to decide whether they wanted to participate in the study or not. I disclosed all the relevant information to the participants. Information was explained to the HCBCs within a group setting, and to the users, primary caregivers and family members individually. I explained to all participants their right to: voluntarily participate in the study, decline participation and withdraw from the study at any point without any consequences to their employment as HCBCs or to their utilisation of the HCBC service.

Written informed consent was obtained from all participants prior to data collection. They read through an informed consent document in their choice of Afrikaans, English or Xhosa (Appendices 3 and 4). Participants were given the opportunity to ask questions related to the study and their involvement. This included their consent to audio recordings of data collection sessions.

Confidentiality was ensured by storing hard copies of findings in a locked cupboard and electronic copies on a password-protected computer. No identifying particulars will be used in the dissemination of data. Participants from the focus group discussion were given a unique number: HCBC 1–5. I wrote down HCBC 1–5, their names and surnames on a separate paper so that I would be able to identify the participants. I provided each of the participants with a different colour-coded ballot paper inscribed with their unique number in the corner on which to write their answers to each question.

For the HCBC users, primary participants were given a number depending on when they were interviewed. For example, if the participant was interviewed first then their unique number would be User 1. The same was done for family caregivers.

Fairness of the study was upheld by treating each participant with the same respect and dignity. Participants were informed that findings from the research might be published. Results will be disseminated through this research assignment. By publication in a peer reviewed journal and during sharing and implementing the recommendations with the various responsible parties.

3.11 SUMMARY

The study is an exploratory, qualitative study. It was conducted in two phases: Phase 1 (HCBCs) and Phase 2 (users of HCBC services and family caregivers). This chapter covered the study setting, sampling procedures and data collection methods. It concludes with ethical considerations related to the study. Data analysis will be presented in the next chapter.

CHAPTER FOUR FINDINGS

4.1 INTRODUCTION

The first aim of the study, to identify who the consumers of the home- and community-based service are, was clearly answered by the home- and community-based carers. The second aim proved to be more challenging. User participants struggled to identify their needs. Thus the needs of the consumers were deduced from user descriptions of the service they received, their experiences of the service, the impact of the service and suggestions for improvement of the service. The themes and subthemes identified from the findings are presented in table 4.1.

Table 4.1: Summary of themes and subthemes

Themes	Subthemes
Theme 1	Consumers of home- and community-based care <ul style="list-style-type: none"> • Community • Family involvement
Theme 2	Consumer experiences of home and community based services <ul style="list-style-type: none"> • Satisfaction • Acceptability • Communication
Theme 3	Impact of service
Theme 4	Services received <ul style="list-style-type: none"> • Medication • Preventive care • Wound care • Self-care • Family training and education • Rehabilitation • Consumables
Theme 5	Need for a seamless health care pathway
Theme 6	Suggestions for improvement <ul style="list-style-type: none"> • Working conditions • Training • Availability of supplies • Continuity

4.2 THEME 1: CONSUMERS OF HCBC SERVICES

The findings showed that any member of the community could use the service and that family members were included in service provision.

4.2.1 Community

There was a general consensus amongst the participant HCBCs that “*the community is the consumer*” of the HCBC service in Caledon. The service is available to the entire community from young to old; everyone is included. No specific diagnosis is necessary.

“Community”(HCBC 1, 44 years)

“Community, for example those who cannot walk.” (HCBC 5, 43 years)

Specific groups in the community mentioned by participants included community members who are socio-economically disadvantaged and cannot afford medical insurance.

“Because a lot of people are underprivileged and don’t have a medical aid.” (HCBC 2, 23 years)

Elderly community members who are faced with specific challenges due to frailness and old age are also consumers.

“Some people are old and cannot get to the clinic.” (HCBC 2, 23 years)

“...the people need the HCBCs, because they cannot walk by themselves, cannot see and cannot wash themselves. In other words they are very dependent on the HCBCs.” (HCBC 4, 43 years)

The service also plays a role in the life of teenagers and assists with family planning and provides guidance to users with regards to healthy living.

“...and then we get some community members who do not know how to maintain a healthy lifestyle at all.” (HCBC 1, 44 years)

4.2.2 Family involvement

As the literature has demonstrated, families play a critical role in home-based care services as they are the primary focus of care and they strengthen the service. It was therefore not unusual to find that many of the HCBCs included the patient, primary family caregivers and family members in the initial assessment and later in the management strategies.

“The family, myself, the people living in the house, the patient, depending on the diagnosis.” (HCBC 2, 23 years)

“[The family is] supposed to play a big role, because sometimes we don’t get to everything.” (HCBC 4, 43 years)

Users agreed that family members were part of the caregiving process.

“They [family members] are definitely included, in the morning when the nurses come their things are already laid out.” (User 7, 50-60 years)

As the HCBCs cannot attend to everything, they rely on the family to continue with care provision and provide training to them in this regard.

“...we must teach the family on how we do it.” (HCBC 4, 43 years)

Some participants had negative experiences related to the involvement of families. According to them some families disregard their care provision role.

“Absolutely nothing, they mean nothing” (HCBC 5, 43 years)

“Yes certain people, but not everyone...If it was my mother, wet her pants (urinated) and waiting for someone else, I will clean my mother.” (HCBC 4, 43 years)

When the participant was asked if the family knew how to provide care; she responded:

“...we prepare them, but they don’t want to be taught.” (HCBC 4, 43 years)

4.3 THEME 2: CONSUMER EXPERIENCES OF HCBC SERVICES

From the responses, it was clear that participants mostly experience the service as positive and that in most instances their needs were met. Three subthemes were identified under service experiences: satisfaction, acceptability and communication.

4.3.1 Satisfaction

Users and family caregivers expressed their satisfaction with the service.

“It’s A for away.” (User 3, 60-70 years)

“Very good.....really they provide an excellent service...see I cannot walk long distances, I have arthritis in my knees, I move slowly. Since they are coming I don’t have to go to the clinic to get my sugar and blood pressure monitored. They have made it very easy.” (User 7, 50-60 years)

There was however a participant who did not have a good experience related to the service.

“Very poor.” (User 8, 60-70 years)

This participant's concerns related to service acceptability issues and showed a need for a more acceptable service.

4.3.2 Acceptability

Service acceptability plays an important role in the overall quality of services and the provision of person-centred care. Acceptability is determined by attitude and behaviour of health care workers as well as by clinical factors. Attitudinal and behavioural factors include aspects like compassion, trust, confidentiality, respect, courtesy, friendliness and sensitivity. Clinical aspects include factors like time spent with the user, explanation provided and trusting the skill of the providers (Mills, Ataguba, Akazili, Borghi, Garshong, Makawia, Mtei, Harris, Macha, Meheus & McIntyre, 2012; Mosadeghrad 2013).

The user who found the service poor had the following to say about the service:

“They were supposed to do a lot of things for me, but they did not do it.” (User 8, 60-70 years)

He indicated that they did not visit him on a regular basis.

“...they don't visit me regularly... they have not been here for two weeks.” (User 8, 60-70 years)

Another participant confirmed this complaint and further indicated that the HCBCs' visits were rushed.

“They always say they are in a hurry; they have more clients to go and wash. They will come on Monday, but they did not come. They did not come regularly. They do not come when it rains.” (Family caregiver 10, 60-70 years)

Contrary to the above experiences many participants experienced the HCBCs' attitudes as acceptable:

“My experience of them is that they are friendly and helpful. When they enter: ‘Good morning, how are you, any complaints?’ then I tell them if I have any complaints.” (User 3, 60-70 years)

“They work carefully with you and they talk to you...When they come they are not in a hurry to go again quickly.” (User 1, 60-69 years)

“They are good, they work with you. They are not afraid of touching you, here and there they are a little scared, but we put them at ease. I cannot complain about them.” (User 7, 50-60 years)

They also relate positive experiences with regard to clinical factors.

“They treat you well and they talk to you...they know how to work with me, and they work well with your wounds.” (User 1, 60-69 years)

An HCBC participant pointed out the importance of confidentiality and that the patient's wishes take priority:

“...sometimes it is private, confidential...Maybe I am HIV, but I don't want my family members to find out yet, at a later stage I will share the information with them.” (HCBC 4, 43 years)

The HCBC participants further indicated that building a trusting relationship with their clients is crucial to service delivery as it enables them to respond to the consumers' needs in times of crises and ensure that they are knowledgeable on the consumers' management plan.

“So that you can have a good relationship with your patient, something might happen to your patient and he does not have any medication and he cannot talk perhaps.” HCBC 4, 43 years)

‘He must trust you, you must win his trust and he must win your trust and you must know on what treatment he is.’ (HCBC 3, 37 years)

One of the building blocks of trust is communication.

4.3.3 Communication

Open communication between consumers and providers is an essential component of a client-centred service (Hussey, 2013). The user participants valued the open communication line and relationship they have with the HCBCs. Their narratives showed that they had the opportunity to voice their opinions, provide guidance to service providers and resolve conflict.

“...sometimes I watch them and if I feel there is something they must know, that I have picked up, for example with washing and I feel something is not right. We have an open relationship with each other. Their [people with SCI] feet become scabrous, so I showed them how the hospital showed me to make it soft and rub it. So we have good communication.” (Family caregiver 7, 50-60 years)

“Staff nurse [the coordinator of the HCBC service] is very sensitive. We had a disagreement where I found them poor, but everything has been sorted out. She made an effort to come to me, it was in the evening and we sorted it out. Now she always asks how she [user] is doing.” (Family caregiver 11, 30-40 years)

Some user participants were confident that if they share their needs and worries with the HCBCs, the carers would address these needs and try to find solutions for them.

“They mean a lot to me, when I am in a situation and I talk to them. Then they go and they come back with advice and plans.” (User 6, 40-49 years)

However, it seems as if in some instances communication can improve:

“What I want is for them to inform you when they will not come on a specific day, if they are on a course or something.” (Family caregiver 11, 30-40 years)

4.4 THEME 3: IMPACT OF SERVICE

Another indication that the needs of consumers were met was that user participants felt that the service had a positive influence on their lives and that it added value:

“100%, it had a big impact.” (User 7, 50-60 years)

“It means a lot to me, for example where I can’t help myself they are there to help. If I must go to the clinic and I cannot make it, then they are there to help then they come around.” (User 1, 60-69 years)

The service reduced the financial burden of families, and assisted the family caregiver.

“...if it had not been for them; I would have had to pay someone to do it...If they did not do it, I would have had to get someone to...a special person to bath me in the morning...” (User 7, 50-60 years)

The user participants felt the service did not only add value to their individual lives, but it is also a resource to the community.

“Having them means a lot to me and to the community as they are a huge source of help. People who can’t move and who can’t get to the clinic.” (User 3, 60-69 years)

The role of the HCBCs might be seen as physical in helping with activities of daily living and monitoring preventive practices, but the participants clearly experienced psychological benefits from their visits as well.

“Yes, just having that conversation with them taking your mind away from the things that is in your head and bothering you.” (User 7, 50-60 years)

“They give you guidance, they talk to you, and they sit with their patients. They don’t just do their job, jump up and leave. If I get home at night then my Aunt [name of a person] would say they came to sit and talk.” (Family caregiver 11, 30-40 years)

4.5 THEME 4: SERVICES RECEIVED

Findings showed a wide array of services delivered which points towards diverse consumer needs. These areas included the delivery of their medication, preventive practices, wound care, self-care, family training and basic rehabilitation, and provision of consumables (for example, adult nappies).

4.5.1 Medication

A number of participants mentioned that the HCBCs brought their medication from the clinic.

“They bring my medication if it is available.” (User 3, 60-69 years)

4.5.2 Preventive care

Participants’ experiences regarding preventive care were varying in nature. Many mentioned the monitoring of blood sugar and blood pressure.

“Yes, they take my blood pressure, and sugar and visit me every other day.” (User 4, 60-69 years)

There were however participants that noted that they had to voice their needs to the HCBCs; there was no initiation from the side of the carers.

“Yes, but you must tell them ‘measure my sugar’...they don’t do it freely, not without being asked.” (User 9, 70-80 years)

It was evident from one participant that the HCBCs also addressed lifestyle choices and provided health education.

“What they prescribed for me is that I must eat a lot of green and boiled foods. I must also make sure that my weight goes down, my weight could probably be the cause of all these things [health problems]... They take my blood pressure, at times they weigh me and they also bring my medication.” (User 6, 40-49 years)

Other participants however answer negatively to questions on whether they received lifestyle education or guidance re stress management.

Other preventive practices were also mentioned:

“Yes with the children’s clinic cards and stuff. They check if the immunisations are up to date.” (User 1, 60-70 years)

4.5.3 Wound care

“They do wound care.” (User 1, 60-70 years)

4.5.4 Self-care

The service supported participants with activities of daily living tasks in which they were dependent.

“They do my nails if it is long, then I say to them cut my nails.” (User 2, 60-69 years)

“They come in the morning then they wash me.” (User 7, 50-60)

Others felt that more assistance could be given with self-care tasks to ease the burden on the family caregiver.

“Basically if they come here and I am at work they can ask if he has been washed and if he has not then maybe they could help with that.” (Family caregiver 2, 30-40 years)

4.5.5 Family training and education

Some of the responses showed that the family caregivers were trained in a number of caregiving practices.

“They have taught and showed me more how to help my mother. I also looked at how they do things so that they don’t have to come every day.” (Family caregiver 1, < 18 years)

But she had very specific needs based on her mother’s condition and wanted more education.

“...how to progress, what my mother must eat every day and how she must drink her medication and how her wounds must be done... They must teach me how to create space in the house that my mother can exercise and walk inside the house. My mother’s hand swells, what should I put on, what should I do, or if my mother’s leg pain or swell what do I have to do? Wounds developed and there is more stuff on the wounds. What must I do? Or what must I apply or put on?” (Family caregiver 1, <18 years)

Other received no education:

“No, they don’t provide training.” (User 9, 70-80 years)

“No, I did it out of my own. They did not have any role.” (Family caregiver 2, 30-40 years)

4.5.6 Rehabilitation

Some participants received basic rehabilitation:

“...and then they give me some exercises...they told what I to do to improve the crookedness of my mouth.” (User 7, 50-60 years)

Others said previously the carers used to do exercises with the clients, but at that moment in time they did not receive any.

“She always did exercises with Uncle [name of person]. Lifted his leg up and down. Forging his arm, but now they do nothing.” (User 9, 70-80 years)

4.5.7 Provision of consumables

“They gave her nappies and stuff.” (Caregiver 11)

4.6 THEME 5: NEED FOR A SEAMLESS HEALTH CARE PATHWAY

The HCBC is supposed to be a bridge between the client and the health facility. The carer is part of the community and first health care contact point. Users can access them for information and guidance. When the needs of the user surpass their knowledge and skills, they must refer the user for further assistance. It seems as if the pathway between user, carer and health facility breaks down.

“I have constant headaches. Now I have pain in my shoulders, where at night the pain moves down to my hands. Then my hands and fingers become numb it feels like pins and needles...They write it down, but it seems as if they are doing nothing about it...they must do their job properly.” (User 9, 70-80 years)

“They have arranged with the clinic that they must give medication until I go to Worcester again, but my daughter was there on Wednesday. Thursday they handed out medication then Aunt [name of person] said that [name HCB carer] must bring my medication, the arthritis medication. I told [name HCB carer] to bring my medication, but she said that no medication came to the HCBC service.” (User 3, 60-70 years)

“...if you tell them your concern, then they must provide feedback from the staff nurse.” (User 9 70-80 years)

The researcher prompted the HCBC participants with regards to referral to other services, should a user need referral. Their lack of response on this matter however, seems to indicate that participants did not know how to refer their clients to other services, such as social services, if they identified a client who would benefit from social services intervention.

4.7 THEME 6: SUGGESTIONS FOR IMPROVEMENT

4.7.1 Working conditions

User participants looked away from their own needs and identified issues related to the working conditions of HCBCs which, if changed, might assist to improve the services and their job satisfaction. The issue of workload seemed to be a challenge, as is so often the case in health care, and participants suggested longer hours to cover the workload.

“What they can do is to extend their working hours. They basically just work from 9:00-13:00 and that is short since they have to go to a lot [of people].” (User 1, 60-70 years)

Some felt that men might be better suited to deal with the physical requirements of some aspects of the job and suggested that the service employ some men.

“They must employ two to three men for the bigger people like me for example. Some of the girls are skinnier and it’s difficult for them, then I phone the service and say don’t send that person tomorrow, because she struggles.” (User 7, 50-60 years)

His wife agreed:

“...as he said if they get more men to get him out of bed and put him in the wheelchair. We are now just three, we have to wait for someone to come and help us. Even if it is only three times, not every day maybe Monday, Wednesday and Friday when they have finished bathing and dressing him then they can put him in the wheelchair that is all we long for. Further they see to all our needs.” (Family caregiver 7, 50-60 years).

A final suggestion that might improve working conditions related to payment:

“They actually do more than what they are being paid for, if they could adapt their salaries just a little bit, just to make them happy as well.” (User 7, 50-60 years)

4.7.2 Training

There might be a need for additional training on specific conditions”

“...to educate the girls more on people like us who are bedridden.” (User 7, 50-60 years)

The training must be transferred to family caregivers:

“Yes, they go for training and are taught how to work with patients. So they can inform me as a family member. Then I know what to do too.” (Family caregiver 1, <18 years)

4.7.3 Availability of supplies

Something to explore is the availability of supplies at the homes of HCBCs, as suggested by one participant. However, the logistical challenges related to this might prohibit it.

“They can for example my mom’s leg, say for instance there is no more stuff left to apply to her leg and the wound must be cared for. Then I could for example go to their home, they must have some stuff at home that they can give to me so that I can apply it to her leg.” (Family caregiver 1, < 18 years)

4.7.4 Continuity

It seems as if continuity might be lacking due to constant rotation of HCBCs.

“...now it is always two new people and everyone does their own thing...They did this initially then they leave two persons for a period of time with him, but nowadays every second day or every day it is someone new.” (Family caregiver 7, 50-60 years)

Whereby the husband responded as follows:

“They say they don’t want the HCBCs and patients to become too familiar with one another. I understand that they have to rotate. You get the hard-working ones and the ones who are lazier. Those who are lazier don’t want to come to me because they have to wash me, take my blood pressure, measure my sugar, rub and do exercises. They just want to come in and sit and check if you took your medication correctly things like that. That is why they rotate.” (User 7, 50-60 years)

They made the following suggestion to improve continuity:

“Maybe they must just come together on one day maybe four of them together... take the two new people through the process...” (Family caregiver 7, 50-60 years)

4.8 SUMMARY

The findings showed that any member of the community could be a consumer of home and community-based care services and that family members are included by the home and community carers in care giving activities. As can be expected from a consumer base that includes every member of the community, consumers had wide-ranging needs. HCBCs tended to a variety of needs from health promotion and prevention, through curative to rehabilitative. Consumers were mostly satisfied with services and in most instances their needs were met. They did indicate unmet needs regarding continuity of care (both from home- and community-based carers and in referral to and communication with other levels of health care). Service acceptability can in some instances improve regarding the keeping of appointments or provision of notification if appointments cannot be kept. The findings also showed that needs of individual consumers were unique and based on their circumstances and the health condition of the patient.

CHAPTER FIVE DISCUSSION

5.1 DISCUSSION

In this chapter the study findings will be discussed through connection with existing literature and exploring possible reasons for findings.

Findings from the study indicated that any member of the Caledon community can be a consumer of the HCBC service in Caledon. Service delivery is not dependent on income, socio-economic status, diagnosis or any criteria other than need. This is in accordance with observations from Aantjies et al (2014) who stated that HCBC has evolved to be a service for all those in need of care at home, rather than a service for people with HIV, as it was in the past.

Family involvement is viewed by the HCBCs as crucial to the sustainability of the HCBC service, and family carers are seen as essential members of the care team. Users agreed with this view. Some family carers also clearly realised their responsibility, interacted with HCBCs, provided care in their absence and even indicated that they would like more training and knowledge to be able to extend the care and exercises they give. Others, in the perception of the HCBCs, seemed to have shifted their responsibility to the HCBC service and disregarded training and guidance. Information that falls outside the scope of this study is needed to come to a real understanding of this issue. Family carers might suffer from burnout, have multiple responsibilities or health problems of their own (Hassan, Visagie & Mji 2011b) which might hamper their ability to provide care and cause them seemingly to neglect or shift their duties.

However, as caring provided by family carers is part of the continuum of care, the inability or unwillingness of family carers to take responsibility will hamper the overall quality of care received by the consumers and might impact their quality of life negatively. Shifting responsibility to the HCBCs also increases *their* workload and might decrease their job satisfaction, since consumer outcomes can be negatively impacted and they might feel unsupported and unappreciated. Mashau *et al.*, (2016) found in a study conducted in the Mutale Municipality (South Africa) that HCBCs experience physical and mental exhaustion. A lack of support for whatever reason from family carers might aggravate this exhaustion, cause frustration amongst the HCBCs and, in conjunction with other factors, might lead to burnout, a condition which HCBCs are at particular risk (Moetlo *et al.*, 2011).

The HCBCs provided a wide range of services from preventive, through curative to rehabilitative care as shown in the findings. These varying and wide-ranging services from HCBCs were also described by Mataure & Thupayagale-Tshweneagae (2013) and Mwai *et al.*, (2013). However, provision of all these services for consumers with varying diagnoses requires substantial knowledge, from knowledge of causes of diseases, to social determinants of diseases, to rehabilitation after life-altering traumas such as stroke or spinal cord injury. It appears to be a huge, and possibly unfair, expectation that this cadre of health care service providers, who have very little training, must deal with all the HCBC users effectively.

It is therefore a compliment to these service providers that so many users gave positive reports of the service. Another acknowledgement is the many areas pointed out that indicate an acceptable service. Health care services often receive criticism for a myriad of challenges such as long waiting times, rudeness and short consultations (Cleary, Birch, Moshabela, & Schneider, 2012; Harris, Goudge, Ataguba, McIntyre, Nxumalo, Jikwana & Chersich 2011). These HCBCs were friendly, and despite what must be a hefty schedule, they took their time to listen to consumers, to the extent that consumers experienced the contact with HCBCs not only as physically beneficial, but also as psychologically helpful.

It could be argued that in some instances the services provided might have only touched the tip of the iceberg of the users' needs. For example, the daughter of the woman who was involved in a motor vehicle accident was trained, but in her opinion, the training did not cover all aspects that she identified as necessary. Her requirements did not seem unreasonable for the family carer of someone who was involved in a motor vehicle accident. However, HCBCs form the first line of health care provision after family carers, and as such their role might be just that: to provide basic support, training, information and management for a wide range of health conditions. It is possible that the HCBCs did not have the depth of knowledge necessary to train the daughter further, and perhaps her expectation was unreasonable.

5.1.6 Provision of further education and training for HCBCs

The participant users' recommendation for further HCBC training in the management of specific conditions would expand the range of health conditions that could be covered. This recommendation is also in agreement with Tsolekile *et al.* (2014), who found that HCBCs, as health educators within their communities, lack knowledge in certain areas. Tsolekile *et al.* recommended that HCBCs would benefit from further education and training to address certain conditions as they are confronted with them on a daily basis (2014). However, they

must operate within a certain scope of practice and will at times be confronted with things which they do not have the ability to address. It is essential that they can identify these situations and they know the appropriate referral pathways and where to source the necessary support.

5.1.7 Provision of training by HCBCs

Findings on the provision of training were mixed, even contradictory. HCBCs felt that they provided training to family caregivers, while some family caregivers said they did not receive training or did not receive enough training. Further exploration of these findings, which were outside the scope of this study, is needed before action can be recommended. There is a need to establish whether this involved only specific individual carers or whether it was a widespread problem. One must also consider that people's perceptions on adequate training differ.

5.1.8 Extend HCBC working hours

Another criticism focused on HCBCs not visiting regularly enough. The HCBCs are currently working five days a week from 08:00–13:00. When one takes the number of consumers (<300) and the diversity of services expected from them into consideration, it is possible to understand how they might be stretched and not always able to maintain their schedule. Thus the recommendation from consumers that the HCBCs work longer hours seems to be a reasonable one. If longer hours are not possible, there might be a need to look at increasing the numbers of HCBCs. Failure amongst HCBCs to keep appointments has already been identified by Cawood and Visagie (2015). Informing a user of a change in schedule is a courtesy to be expected.

5.1.9 Communication

Communication is an essential part of trusting relationships and client-centred health care. Communication between users and HCBCs was seen as a valuable component of the service. Users had an open communication line, were able to voice their needs and concerns, and received feedback. However, it seems as if a communication breakdown has occurred between the HCBCs and other levels of health care service provision. This might be due to HCBCs' lack of knowledge of referral pathways as demonstrated, or the fact that they are not employed by the provincial Department of Health. However, it is essential that they have regular formal and informal contact with staff at the clinic where they can bring users' concerns and questions, and obtain answers or make appointments.

5.2.0 Confidentiality

Confidentiality was seen as a high priority by HCBCs. Diagnosis is only disclosed once patients feel comfortable with disclosure to families. As HCBCs see this as a priority, it contributes to building a trusting relationship with their users. They see relationship building as crucial to their service, as it enables them to become more knowledgeable about their users' needs and treatment plans.

5.2.1 Employ male HCBCs

Currently all the HCBCs are women. The nature of the work (e.g. lifting and turning consumers who are paralysed or have contractures) sometimes requires physical strength. It was felt that if the service employed men as well, they might find the physical nature of some of the tasks easier and that it might relieve the physical strain on the women.

5.2.2 Consistency for relationship-building

Users would like the HCBCs to be more consistent during home visits and limit the rotating of HCBCs. Receiving service from the same HCBCs for a period of time enables users to build a rapport with the HCBCs and ensure continuity. This seems a reasonable request and while there are good reasons for rotation of workers, it might be beneficial to all to determine specific times for rotations, for example quarterly. As suggested by consumers, when providers do rotate there is a need for communication and a proper handover between HCBCs.

5.2.3 Need for pre-emptive service

There was an overall impression of a responsive rather than a pre-emptive service. Being pre-emptive is especially important for health promotion and disease prevention. Findings indicated that some users received health promotion and others not. It might be that information was only provided to those in obvious need, such as an overweight person with arthritis, but carers neglected to provide information in other instances.

CHAPTER SIX

LIMITATIONS, RECOMMENDATIONS AND CONCLUSION

6.1 LIMITATIONS

Firstly, the study was limited by the small sample size utilised as the service provided care to approximately 300 users. However, data saturation was obtained. Secondly, the HCBC coordinator identified potential participants for the study. This group could have been biased as the participants identified could have been the ones who had received relatively good services from the HCBCs or the coordinator knew they would give positive feedback. The data that was collected from the focus group and semi-structured interviews was concrete data; no deep rich information was gathered from the participants. While aware of this even during the data collection process, I struggled to move beyond concrete answers even when I asked a lot of guiding questions.

6.2 RECOMMENDATIONS

My recommendations, based on this study, are as follows:

- The Department of Health must develop a scope of practice guidelines, or, if this exists already, then it must ensure that users and HCBCs know, understand and implement it.
- Enhance the education of HCBCs on specific health conditions within this scope of practice to enable HCBCs to address a range of health-related needs.
- Employer can improve services by addressing the following:
 - Increase stipend of HCBCs
 - Increase numbers of HCBCs or working hours of current carers
 - Employ male caregivers to reduce burden of caregiving.
- HCBC coordinators must develop structured contact platforms with clinic staff to start referral pathway and ensure continuation of services.
- Empower HCBCs with knowledge on referral pathways and sources of support within the Department of Health and with other governmental departments
- HCBC Coordinators must decide on fixed periods e.g. quarterly before HCBCs rotate between clients. Ensure continuity when HCBCs rotate.
- Health promotion is such a vital component of primary care that it might be helpful that HCBC Coordinators provide HCBCs with some form of checklist or booklet with health promotion questions to be asked and information to be shared.

- Further studies are recommended on the reasons why family carers were sometimes perceived as negligent of their responsibilities and negligent of the provision of training to family carers by HCBCs.

6.3 CONCLUSION

The HCBCs provide a valuable service to the community of Caledon. Any member of the community may use the service, and can thus be a consumer of the HCBC service. For example, people with chronic illnesses, or people with disabilities, along with their families and family carers all have access to HCBC. The needs of the users include an open communication line, provision of medication and consumables, family training, education, rehabilitation and continuity of services. Furthermore, these needs are mostly being met and most users and their family/carers had positive experiences related to the service. However, the study also identified the gaps related to further education of HCBC workers, their interaction with family carers and referral to other services.

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APPENDICES

Appendix 1: Ethics approval letter



UNIVERSITEIT-STELLENBOSCH-UNIVERSITY
jou kennisvermogen • your knowledge partner

Approved with Stipulations New Application

25-Feb-2013
Valenzia, Mackenzie V
Victoria Street
Stellenbosch
Stellenbosch, WC

Ethics Reference #: S12/11/309

Title: Consumers of the Home and Community Based Care service in Caledon: Identifying who they are and what their needs are.
Dear Ms Mackenzie Valenzia,

The New Application received on 27-Nov-2012, was reviewed by members of Health Research Ethics Committee I via Expedited review procedures on 21-Feb-2013.

Please note the following information about your approved research protocol.

Protocol Approval Period: 21-Feb-2013 -21-Feb-2014

The Stipulations of your ethics approval are as follows:

1. Indicate on each consent and assent form exactly how much time will be required from participants for each activity.
2. There are some paragraphs in the parental consent that refer incorrectly to parent's participation. It is the child's participation that the researcher is seeking consent for.

Please remember to use your protocol number (S12/11/309) on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:

Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372

Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthires@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and documents please visit: www.sun.ac.za/rds

If you have any questions or need further assistance, please contact the HREC office at 0219389657.

Included Documents:

Investigators cv

Protocol
Supervisors declaration
Supervisor cv
Investigators declaration
Checklist
Application Form

Sincerely,



Franklin Weber
HREC Coordinator
Health Research Ethics Committee I

Appendix 2: Approval letter Department of Health



STRATEGY & HEALTH SUPPORT
Health.Research@westerncape.gov.za
tel: +27 21 483 6857; fax: +27 21 483 9895
5th Floor, Norton Rose House, 8 Riebeeck Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: RP051 /2013
ENQUIRIES: Ms Charlene Roderick

25 Eight Avenue
Bergsig
Clendon
7230

For attention: **Valencia Mackenzie**

Re: Consumers of the Home and Community Based Care service in Caledon: Identifying who they are and what their needs are

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact the following people to assist you with any further enquiries in accessing the following sites:

Caledon CHC Ms R Zondo Contact No. 028 212 1512

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final report within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. The reference number above should be quoted in all future correspondence.

We look forward to hearing from you.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Dr NT Naledi'.

DR NT Naledi
DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE: 28/6/2013
CC MS W KAMFER

DIRECTOR: OVERBERG

Page 1 of 1

Appendix 3: Information and informed consent document

Title of the research project:

Consumers of the Home- and Community-Based Care service in Caledon: Identifying who they are and what their needs are

REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: Valenzia Mackenzie

ADDRESS: 25, Eight Avenue Caledon, 7230

CONTACT NUMBER: 082 264 6305

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please feel free ask any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Committee for Human Research at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

The aim of this research study is to determine, who are the consumers' utilizing the HCBC service, but also to determine their needs. The study will be divided into two phases, due to its nature. The study will be conducted with Home and Community Based Carers working in the Caledon Community as well as individuals receiving services from the Home and Community Based Care service along with a primary caregiver and/or family member. Since, 2005 the Home and Community Based Care service has been providing care to the Caledon Community. No research has been done with regards to the identification of consumers (beneficiaries) and their needs using the Home and Community Based Care services in the Western Cape. The research therefore creates the opportunity to determine who are using the

Home and Community Care service and what their needs are. The information from the study will help to enable providers to integrate consumers and their needs in the delivering of care. The study will be conducted through focus group discussions with Home and Community Based Carers and interviews with consumers.

Why have you been invited to participate?

You have been invited to participate in the study because you are a Home and Community Based Carer providing services to the Caledon Community. The researcher would like to give you the opportunity to identify who you see as the consumer of the Home and Community Based service. With your participation will help with the identification and integration of consumers.

What will your responsibilities be?

You will be responsible to take part in focus group discussion with other Home and Community Based Carers. The study will require that you give up on some of your personal time to take part in the discussion. During the focus group discussions you will engage with other Home and Community Based Carers and express your views and ideas. The researcher will guide the focus group discussion and the discussion will be between 1-2 hours.

Will you benefit from participating in the study?

Home and Community Based Carers will benefit from the study to enable them to include all consumers in the caring process.

Are there risks in taking part in the study?

No risks are involved with your participation in the study.

Will you be paid to take part in this study and are there any costs involved?

No participant in the study will be paid for their participation. There will also be no costs involved with your participation.

Is there anything else that you would like to know or do?

- You can contact the researcher Valenzia Mackenzie at 082 264 6305 or 041 397 7735 if you have any questions

- You can contact the Committee for Human Research at 021 938 9207 if you have concerns and complaints related to the study.
- As a participant in the study you will receive a copy of the information and consent form for your personal records.

Declaration by participant

By signing below, I agree to take part in a research study entitled “Consumers of the Home and Community Based Care service in Caledon: Identifying who they are and what their needs are”

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 20013

.....

Signature/thumbprint of participant

.....

Signature witness

Declaration by investigator

I Valenzia Mackenzie declare that:

- I have explained the information in this document to
.....
- I have encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above.

Signed at (*place*) on (*date*) 2013.

.....

Signature of investigator

.....

Signature of witness

Appendix 4: Information and informed consent document

Title of the research project:

Consumers of the Home and Community Based Care service in Caledon: Identifying who they are and what their needs are

REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: Valenzia Mackenzie

ADDRESS: 25, Eight Avenue Caledon, 7230

CONTACT NUMBER: 082 264 6305

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please feel free ask any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Committee for Human Research at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

The aim of this research study is to determine, who are the consumers' utilizing the HCBC service, but also to determine their needs. The study will be divided into two phases, due to its nature. The study will be conducted with Home and Community Based Carers working in the Caledon Community as well as individuals receiving services from the Home and Community Based Care service along with a primary caregiver and/or family member. Since, 2005 the Home and Community Based Care service has been providing care to the Caledon Community. No research has been done with regards to the identification of consumers (beneficiaries) and their needs using the Home and Community Based Care services in the Western Cape. The research therefore creates the opportunity to determine who are using the

Home and Community Care service and what their needs are. The information from the study will help to enable providers to integrate consumers and their needs in the delivering of care. The study will be conducted through focus group discussions with Home and Community Based Carers and interviews with consumers.

Why have you been invited to participate?

You have been invited to participate in the study because you are receiving services from the Home and Community Based Care service in Caledon or you are a primary caregiver and/or family member of someone who is receiving services from the HCBC.

What will your responsibilities be?

You will be responsible to answer questions during the interviews to the best of your ability. The study will require that you give up on some of your personal time to take part in the study. The researcher will administer the interview and it will be between 30-45 minutes.

Will you benefit from participating in the study?

Persons receiving services from the Home and Community Based Care service, their primary caregivers and/or family members will be able to raise their voice and express their needs. All together it will improve Home and Community Based Care service to integrate and organise care for all members of the community using the service.

Are there risks in taking part in the study?

There are no risks involved with your participation in the study. Interviews will take place in your home environment. It is however, anticipated that during the interviews feelings and emotions might be elicited through sensitive questions with regards to your needs. There are however counsellors in place to assist you to handle the emotional stress.

Will you be paid to take part in this study and are there any costs involved?

No participant in the study will be paid for their participation. There will also be no costs involved with your participation.

Is there anything else that you would like to know or do?

- You can contact the researcher Valenzia Mackenzie at 082 264 6305 or 041 397 7735 if you have any questions

- You can contact the Committee for Human Research at 021 938 9207 if you have concerns and complaints related to the study.
- As a participant in the study you will receive a copy of the information and consent form for your personal records.

Declaration by participant

By signing below, I agree to take part in a research study entitled “Consumers of the Home and Community Based Care service in Caledon: Identifying who they are and what their needs are”

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to withdraw from the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 20013

.....

Signature/thumbprint of participant

.....

Signature witness

Declaration by investigator

I Valenzia Mackenzie declare that:

- I have explained the information in this document to
.....
- I have encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above.

Signed at (*place*) on (*date*) 2013.

.....

Signature of investigator

.....

Signature of witness

Appendix 5: Participation information leaflet and assent form

TITLE OF THE RESEARCH PROJECT:

Consumers of the Home and Community Based Care service in Caledon: Identifying who they are and what their needs are

PRINCIPAL INVESTIGATOR: Valenzia Mackenzie

ADDRESS: 25, Eight Avenue Caledon, 7230

CONTACT NUMBER: 082 264 6305

What is Research?

Research is something we do to find new knowledge about the way things (and people) work. We use research projects or studies to help us find out more about disease or illness. Research also helps us to find better ways of helping or treating children who are sick.

What is research project all about?

The aim of this research is to determine, who are the persons using the Home and Community Based Care service in Caledon as well as their needs. The study will be have two sections to get all the information from everyone taking part in the study.

Why have I been invited to take part in this research project?

You have been invited to take part in the study because you are receiving services from the Home and Community Based Care service in Caledon.

Who is doing the research?

I, Valenzia Mackenzie am doing the research. I am a student and this research project is part of my studies.

What will happen to me in this study?

During the study you will be asked questions that you need to answer. The questions will be around what you want from the Home and Community Based Care service. All the questions asked and answered will be recorded on a voice recorder. The length of time that you will be spending to answer questions will be between 30-45 minutes.

Can anything bad happen to me?

Nothing bad can happen to you, except that you might feel that you want to cry.

Can anything good happen to me?

You will be able to say what you want from the Home and Community Based Care service. This will help the service to provide in you want.

Will anyone know I am in the study?

No one will know you took part in the study. All the information from the questions you asked will be kept safely away from everybody else.

Who can I talk to about the study?

- You can phone the researcher Valenzia Mackenzie at 082 264 6305 or 041 397 7735 if you have any questions
- You can phone the Committee for Human Research at 021 938 9207 if you have any problems with the study.
- As someone taking part in the study you will receive a copy of the information and consent form that you can keep.

What if I do not want to do this?

You have the choice to take part in study or not, even if your parents have agreed that you can take part in the study you can choose. At any point in the study, you can stop taking part in the study without getting into any trouble.

Do you understand this research study and are you willing to take part in it?

yes

No

Has the researcher answered all your questions?

yes

No

Do you understand that you can pull out of the study at any time?

yes

No

Signature of child

Date

Appendix 6: Focus Group Discussion Guide

- 1) Who are the consumers of the HCBC service in Caledon?
- 2) Why would they be seen as the consumer of the service?
- 3) Explain the procedure that happens when you receive a new referral?
- 4) Who do you include in your initial assessment and why?
- 5) Who do you include in your care provision of the client?
- 6) What role do primary caregivers and family members play in the service?
- 7) If a person has a range of difficulties irrespective of the severity for example with walking, communication and cognition, but they still have the ability to direct their care, who would be the consumer?
- 8) If a person has a range of difficulties irrespective of the severity for example with walking, communication and cognition, but they do not have the ability to direct their care, who would be the consumer?
- 9) If a person is healthy and they function independently in their community or home environment, but they however still receive services from the HCBC, who would be the consumer?
- 10) Explain the importance and benefits of the identification of consumers of HCBC service?

Appendix 7: Interview Schedule**Section A: Primary Participants****Code:** _____**Section A1: Socio-demographic information**

1) Gender

- i. Male
- ii. Female

2) Age

18-19	20-29	30-39	40-49	50-59	60-69	70+
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3) Race

White	Coloured	African	Indian	Other
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4) Home Language

Afrikaans	English	Xhosa	Other
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5) How long have you been receiving services from the HCBCs?

< 1 year	2-3 years	4-5 years	> 5 years
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Section A2: Primary Participants' needs**Topic 1:** Experiences of the service

Tell me about how you have experienced the HCBC service?

Examples:

Topic 2: Care

In what areas of your life did the HCBCs help you? Did the service make a difference in your life?

Prompt: What difference did it make?

Topic 3: Meaning

Tell me about what the HCBC service has meant to you or means to you?

Examples:

Topic 4: Service Provision

Tell me how satisfied you were with the care and services that you received?

Prompts: Did it meet your needs?

Topic 5: Needs of the primary participant

Tell me what your needs were that you feel HCBCs could have helped you with?

Prompt:

- 1) **Personal Needs** \Rightarrow Physical (blood pressure & blood sugar measurements)
 \Rightarrow Psychological (insight into condition/stress/depression/motivation)
- 2) **Environmental Needs** \Rightarrow Physical (safety & security; water & sanitation; changes made to home environment)
 \Rightarrow Psychological (adjustment to condition; support system)
- 3) **Lifestyle needs** \Rightarrow diet; exercise & rest; recreational
- 4) **Needs with regards to Activities of daily living** \Rightarrow mobility, washing, eating & dressing

Which of these needs were most important?

Topic 6: Recommendations

What do you think the HCBC service can do to meet the needs of their consumers/beneficiaries?

Thank you for your participation. Do you have any questions?

Section B: Secondary Participants

Section B1: Socio-demographic information

- 1) Gender
 - i. Male
 - ii. Female

- 2) Age

<i>18-19</i>	<i>20-29</i>	<i>30-39</i>	<i>40-49</i>	<i>50-59</i>	<i>60-69</i>	<i>70+</i>
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- 3) Race

<i>White</i>	<i>Coloured</i>	<i>African</i>	<i>Indian</i>	<i>Other</i>
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- 4) Home Language

<i>Afrikaans</i>	<i>English</i>	<i>Xhosa</i>	<i>Other</i>
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- 5) What is your relationship to the client? _____

- 6) How long have you been providing care to the client?

<i>< 1 year</i>	<i>2-3 years</i>	<i>4-5 years</i>	<i>> 5 years</i>
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- 7) How much care do you provide on a daily basis?

<i>1-3 hours</i>	<i>3-6 hours</i>	<i>6-9 hours</i>	<i>> 9 hours</i>
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Section B2: Needs of secondary participants

Topic 1: Care

What impact has the HCBC service had on your life? How has the service helped you?

Prompt: caregiving; support

Examples

Topic 2: Needs

What are your needs?

Prompt: Personal; environmental

Topic 3: Assistance

What needs do you think HCBCs can assist you with? How must they go about meeting your needs?

Examples

Topic 4: Identification of needs

What benefits do you think the identification of the consumers'/beneficiaries' needs plays in care provision?

Examples

Topic 5: Recommendations

What do you think the HCBC service can do to meet the needs of their consumers/beneficiaries?

Thank you for your participation. Do you have any questions?